

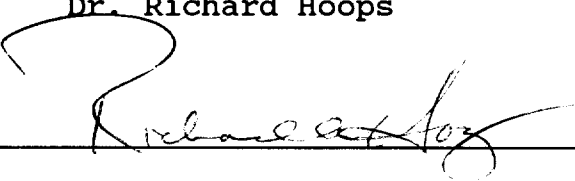
A Survey of Parents of Hearing-Impaired Children

An Honors Thesis (HONRS 499)

by

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When parents suspect a hearing loss in their child, they generally seek professional help. They are looking for answers to their questions and doubts. The problem is that they often do not find the answers right away or they are given the wrong answers. This leads not only to frustration for the parents, but it also leads to the loss of valuable time for aid in language development for the child. This presents a problem that this researcher wishes to discuss--our doctors and pediatricians are not well equipped with the knowledge of hearing impairments. It is the purpose of the research presented here to demonstrate the reality of this problem. There is, however, another dimension of diagnosis that is overlooked--the area of parental reactions to the diagnosis and their need for support and information. Therefore, the research presented here also includes information concerning this other dimension. This researcher decided that a questionnaire sent to several parents of hearing impaired children would prove conducive in obtaining information relevant to those who are responsible for the diagnosis and therapy for hearing impaired children.

The purposes of the questionnaire sent to parents of hearing impaired children were to discover what could be done to aid diagnosis of hearing impairment at the earliest age possible; what information should the parents be given about the hearing loss and possible correction or therapy

techniques; and, what information on support is available to the parents. Before looking at the results of the questionnaire, this researcher will present some information and statistics that validate the results found in this research.

Parents, or relatives, generally suspect a hearing loss in the child when he is between the ages of zero to two years (Hass, et al 1982,19-20). The diagnosis, however, comes later than the suspicion. Research done by Vernon and Wallrabenstein (1984,1-8) showed the age of diagnosis to be eighteen months to three years. The study by Haas and Crowley showed a time delay of six months to two and a half years between the suspicion and diagnosis. Also, the study done by Martin et al reports suspicion in the first year of life and diagnosis of a child's hearing impairment between the ages of thirteen and twenty-four months. These studies demonstrate that for one reason or another, the child is not diagnosed at the earliest possible date. In fact, both the Haas/Crowley and Williams/Darbyshire (1982) surveys indicated an average of four steps between suspicion and diagnosis. Research done by Williams and Darbyshire indicated that "the reported responses of family doctors in the majority of cases led to postponing a diagnosis of hearing impairment" (1982,27). Several doctors (40%) told parents to "wait and see"; some (28%) gave incorrect reasons for the child's behavior but referred the parents to a specialist; and, several others

(32%) immediately referred the parents to a specialist (Williams et al 1982,27). However, forty percent were told to "wait and see." That means forty percent of the children were not diagnosed at the earliest possible date. Lass et al (1986,336) indicated that several professionals--teachers, special educators, physicians and rehabilitation counselors--have deficiencies in knowledge of and exposure to hearing loss. Vernon and Wallrabenstein (1984,1-8) suggest some other reasons for the delay in diagnosis: deafness is "invisible,"--difficult to detect; the child may react to loud noises indicating the presence of hearing; and, the parents' complaints are the same as those with hearing children. Nevertheless, they also conclude that, "most medical practitioners are unaware of the various etiologies of congenital deafness that may serve as warning signs of its presence." The information presented here suggests the delay in diagnosis is due in part to the professional's lack of knowledge and experience concerning hearing impairments.

Once the diagnosis is made, the parents' reactions are basically similar. There are reactions of shock, bewilderment, frustration, sorrow, anger, guilt, and of course, denial. The studies done by Martin et al and Vernon and Wallrabenstein both indicate these reactions; however, the study done by Martin et al carries the information one step further--it also questioned audiologists on how they felt the parents reacted to the diagnosis of hearing impairment in

their children. Although the findings were similar, there was one major difference--audiologists saw parents as denying the diagnosis more often than the parents did. This might indicate the need for the diagnoser to better understand the parents' reactions. If the parents have already accepted the diagnosis, they would be ready for important information on what can be done for their child and what types of support are available. They certainly would not want someone to continue trying to convince them of the loss while neglecting the information. What parents do need is counseling for coping with and understanding their child's condition. They need support, encouragement and basic factual information concerning the hearing loss (Vernon et al, 1984,1-8). They also need a professional who explains the situation in language they can understand--not a bunch of jargon that leaves them confused and feeling dumb (Korsch, 1972,66). The survey by Martin et al provided four major counseling improvements. First, the diagnoser needs to possess "positive counselor characteristics"--supportive listening, helping with working through emotions, offering realistic hope for the future, and spending time with them. Second, there needs to be improvement in services. There should be immediate and ongoing services for the entire family. Group and individual counseling should be available, preferably by another parent of a hearing impaired child. Third, parents need information on available services, remediation, realistic expectations,

and on the importance of early amplification and education for the child. Finally, parents need the opportunity to meet other parents of hearing impaired children (Martin et al, 1987,31-32). Now that we have a reference, we can look at the results of this researcher's questionnaire.

METHOD

A questionnaire was sent to 65 parents of hearing impaired children. The names of the parents were obtained from selected lists from audiologists and teachers of the hearing impaired. The questionnaire consisted of multiple-choice items, fill-in-the blank items and an essay question designed to elicit information about diagnosis, parental feelings, information given, etc. The results were tallied on a percentage basis and were viewed to obtain a general idea of how doctors, diagnosticians and therapists can better aid the hearing impaired. Several questions encouraged more than one answer; therefore, in some cases, the number of responses exceeded the number of respondents.

RESULTS

Fifteen (23%) of the 65 questionnaires sent to parents were returned. All of the questionnaires returned were answered by the mothers. The respondents were all located in

Indiana in the cities of: Muncie, Richmond, Albany, Yorktown, New Castle, and Alexandria. The remaining information obtained by the questionnaire is summarized under the following categories: 1)Diagnosis, 2)Parent reaction, 3)Approach, 4)Information, 5)Method of communication, 6)Schooling, and 7)Interviews.

Diagnosis

The questionnaire responses indicated that half the parents first suspected a loss of hearing during their child's first year of life and obtained professional consultation at that time. There were also a number (36%) of parents who did not suspect a hearing loss until the child was between the ages of two and four. The main reason (64%) parents suspected a hearing loss was because of delayed language development. Other reasons were: "child seemed to hear, but did not respond to instructions or answer questions" (50%), and "the child did not respond to noise (name called, loud noises, etc.)" (43%). Some of the other reasons for suspicion of loss were: "could not hear on phone", "meningitis", "sporadic responses complicated by a mental ability factor", and "teachers mentioning a problem". Once the parents sought professional help, the majority (43%) took their children to a family doctor. Thirty-six percent went to an audiologist and an equal number went to a pediatrician.

During the first consultation with a professional, fifty-seven percent of the parents were told to take their child to a specialist; twenty-nine percent were instructed to wait awhile and see what happened; fourteen percent were informed their child had a hearing loss and twenty-one percent were given various explanations such as "swimmer's ear", "child was stubborn" or even "there was no hearing loss".

After the consultations the responses of the parents were: took child to specialist (64%); waited awhile then took child back to a professional (21%) or took their child to another professional in hopes that the diagnosis of a hearing loss was incorrect (14%). Some parents answered "other" and said they went to various clinics such as Riley and Ball State; however, they all saw specialists and are therefore included in the group that took their child to a specialist. In most cases (64%) an audiologist was the diagnoser. Doctors provided twenty-one percent of the diagnoses and speech pathologists provided fourteen percent.

The results of the diagnosis portion of the questionnaire indicates that several parents (36%) took their child to an audiologist; however, seventy-nine percent took their child to either their family doctor or pediatrician. This suggests that the majority of children thought to have hearing problems are first examined by someone who has little expertise in hearing losses. The results also indicate that half the children, after initial contact with a non-specialist, were

not sent to a specialist or were even proclaimed as having no hearing problems. Although some parents took their child to see a specialist, twenty-two percent waited to see what happened. This means twenty-two percent of the children were not diagnosed at the earliest possible date. This implies the need for doctors and pediatricians to be better informed about hearing loss.

Parent reactions

The majority of the parents were relieved that it was discovered their child had a hearing loss that could possibly be aided or corrected (79%). About half (49%) of the parents felt sad when the diagnosis was given. Two other reactions were shock and anger (36%). Only fourteen percent of the respondents reacted to the diagnosis with denial. One person responded with "other" but did not state what the reaction was (See table 1). There were a few parents (21%) who added that they were either mad or sad about the time wasted between suspicion and diagnosis of a hearing loss as a result of misdiagnosis or a prescription of "wait and see." The reactions mentioned above allow us to see that there are several types of reactions to a diagnosis of hearing loss in a child. Although it might be expected that several more parents would react with denial, only two out of fifteen did. Those who are diagnosing hearing loss should keep this in

mind. They should be aware that denial is possible but relief, sadness, shock and anger are much more common reactions.

Table 1

<u>Reaction</u>	<u>Percent</u>
Relief	79%
Sadness	43%
Shock	36%
Anger	36%
Other (not stated)	7%

Approach

Most of the respondents (79%) felt the diagnoser was compassionate and understanding. Twenty-nine percent felt the diagnoser was very blunt. Twenty-nine percent also felt the diagnoser was sympathetic. Overall, the diagnoser's approach when informing the parents their child had a hearing loss was considered to be very good. Diagnosticians must continue to realize that the diagnosis of hearing loss is very difficult for a parent to handle. An abundance of understanding is necessary for the sake of the parents.

Information

A large portion of the respondents (71%) felt they were informed very well about the diagnosis and correction available (See table 2). However, there were twenty-one percent who did not feel well informed at all and seven percent who were poorly informed. Most of the parents were informed about the type and degree of loss. Over half the parents were given possible methods of correction. Half the parents were given a diagnosis and then made appointments to discuss details, therapy and correctional methods. Several parents were given an idea of what to expect, but only a few parents were given information about support groups.

Table 2

Information

<u>Given</u>	<u>Percent</u>
Type of hearing loss	64%
Degree of hearing loss	64%
Methods of correction	57%
Diagnosis and appointment	50%
What to expect	43%
Support groups	14%
Other	29%

(surgery, sent to Riley for testing (2), report sent to doctor)

In the questionnaire, parents were asked to discuss any information they thought should have been given to them at the time of diagnosis and discussion of correction and therapy. Their answers were varied, but all of them stressed important points: parents should be encouraged to work with their children on language skills; should be informed if hearing aids could be of assistance; should have all options, pros and cons, of aids explained to them; should be given information on therapy and treatment; should have the impairment explained to them; and, should be informed if the hearing could be expected to improve with or without an aid.

Method of communication

The number of children who use total communication is about the same as those who use oral communication. This is important because it helps indicate the role of the parent in the home. If total communication is used, the parents usually need to learn some sign language to be able to communicate with their child.

Schooling

The children of the respondents all attend a school that is either a school for the deaf, a school with a major program for hearing impaired students or a school with some sort of

a resource room. This indicates that parents do want their children to have the help they need to be successful and independent individuals.

Interviews

The questionnaire asked if the parents would be willing to participate in an interview. The majority of the parents (79%) said they would participate in an interview. This gives some indication of where the parents are in respect to discussing a family situation that includes a hearing impaired child. This could also indicate a desire to improve the quality of diagnosis, therapy, etc. that other parents and children will receive in the future.

Conclusion

Overall, the questionnaires returned indicated some satisfaction with the diagnoser's approach in giving the diagnosis. The responses spoke well for the diagnoser's attitude; however, they also indicated there was a lack of information given at the time of diagnosis concerning support groups. Being told your child is hearing impaired and then not having anyone to talk with who has been through a similar situation does not seem like a very easy thing to go through. Diagnosticians should try to understand this and give parents any

information they can about support groups. The majority of the parents responding indicated that their child was diagnosed between the ages of 0-4. This is a time of great development and change for most children. When this already difficult time is made harder by hearing impairment, most parents appreciate the added support.

Another issue to keep in mind is how well family doctors are trained in ear examinations and diagnosis. Almost half of the respondents took their children to their family doctor when they suspected a loss. Twenty-nine percent of the parents were told to wait and see what happened. Twenty-one percent were given such answers as: "It's swimmer's ear"; "your child is stubborn"; and even "there is no hearing loss". This is an important point because most of the children were at a crucial age of language development when the professional gave them these answers. If the parents waited or were satisfied with the above conjectures, critical time periods for language development aid were lost.

The topic of support groups seems important enough for comparison to another survey conducted by Martin et al (1985). The survey they sent out contained several similar aspects as the one presented here, one of which is the topic of support groups. The Martin et al survey reached the conclusion that ". . . many of the counseling needs of parents of hearing-impaired children are not being met adequately" (Martin et al, 1985,32). Parents in their survey wanted

information about "coping strategies . . .and ways to meet other parents of hearing-impaired children" (Martin et al, 1987,30).

All humans are imperfect. We all have areas in which we need to improve. The research presented here is an effort to aid those who are involved with the diagnosis and therapy of hearing impairment to gain further information on areas in which the parents of hearing impaired children have indicated a need for change.

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APPENDIX A:
Letter to parents



Ball State University

College of Sciences and Humanities
Department of Speech Pathology and Audiology

STUDENT QUESTIONNAIRE
by
REBECCA NILES

Dear Parents:

Hello! My name is Rebecca Niles and I would like your help in some research I am doing. I am attempting to find out how parents are informed of their child's hearing impairment, how they were aided in the adjustment, what kind of methods were used to aid the child, and some other general questions that help to make the above questions of value. The questionnaire is by choice only! However, I would appreciate your participation. My purpose in asking these particular questions is to find out how the diagnoser and therapists can better serve the clients they work with. You are in no way obligated to answer any questions which you are uncomfortable with; nevertheless, answering all the questions (excluding the optional section) will make this questionnaire more valid and complete.

Please take a moment to consider what I am asking of you. The questionnaire should take less than ten minutes and would be of value to you and others who are making the adjustment to raising a hearing impaired child. Perhaps you feel you no longer need help in adjusting. Then, please complete this questionnaire to help others who are making the adjustments.

Thank you so much for your time and consideration. Feel free to make any additional comments on the final page of the questionnaire.

Sincerely,

Rebecca Niles

Rebecca Niles

Return to: Hoops--Speech Pathology
Ball State University
Muncie, Indiana 47306
(Return envelope enclosed)

APPENDIX B:
Questionnaire



Ball State University

College of Sciences and Humanities
Department of Speech Pathology and Audiology

QUESTIONNAIRE

DIRECTIONS: Please read each question carefully and circle the answer (or answers) that best applies.

1. How old was your child when you first suspected they had a hearing loss?
 - A. 0-1 years
 - B. 2-4 years
 - C. 5-9 years
 - D. 10 or older
2. What were the reasons why you thought there was a problem?
 - A. Did not respond to noise (name called, loud noises, etc.)
 - B. Seemed to hear, but did not respond to instructions or answer questions.
 - C. Responded only to loud noises or selective noises (high or low pitches).
 - D. Was not speaking at the suggested time for language development.
 - E. Other _____
3. Who did you take your child to when you suspected a loss?
 - A. Family doctor
 - B. Audiologist
 - C. Pediatrician
 - D. Other _____
4. What did your doctor or audiologist tell you?
 - A. Wait awhile and see if they speak soon.
 - B. Take them to a specialist.
 - C. Your child has a hearing problem.
 - D. Other _____
5. What action did you take?
 - A. Waited awhile and when problems continued, took them back to a doctor.
 - B. Took them to a specialist as directed.
 - C. Took them to another doctor or specialist even though instructed to wait awhile.
 - D. Took them to another doctor/audiologist in hopes of a report of no hearing problem.
 - E. Other _____
6. When you found out your child had a hearing loss, what was your reaction?
 - A. Shock.
 - B. Anger.
 - C. Denial.
 - D. Relief that you had found out something was wrong and could possibly be corrected or aided.
 - E. Sadness.
 - F. Other _____



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7. Who was the diagnoser?
- A. Audiologist.
 - B. Speech Pathologist.
 - C. Doctor.
 - D. Other _____
8. How did they tell you about your child's hearing loss?
- A. Very bluntly.
 - B. Compassionately.
 - C. Regretfully.
 - D. Sympathetically.
 - E. Rudely and uncaring.
 - F. Other _____
9. What information did they give you at the time of the diagnosis?
- A. Type of hearing loss. Conductive Sensorineural
 - B. Degree of loss.
 - C. Possible methods of correction.
 - D. Support groups.
 - E. Diagnosis and an appointment to discuss details, therapy and correctional methods.
 - F. What to expect.
 - G. Other _____
10. How well did you feel you were informed about the diagnosis and correctional and therapeutic methods?
- A. Very well.
 - B. Okay.
 - C. Poorly.
 - D. Not informed well at all.
11. What do you wish you would have been told concerning your child's diagnosis?
- _____
- _____
- _____
- _____
12. How well do you feel you are currently handling the situation as compared to your initial reaction?
- A. Handling the situation much better.
 - B. About the same as initial reaction.
 - C. Handling the situation worse than initial reaction.
 - D. Other _____



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13. What method was used with your child in correcting or helping the problem?
A. Total communication.
B. Oral communication.

14. How old is your child now?

15. Where does your child attend school?

The following part of this questionnaire is OPTIONAL.

16. Name _____

Address _____

Phone number _____

17. Would you be willing to participate in a personal interview?
A. Yes.
B. No.

If you would like to see the results of this questionnaire, they will be available at the speech and hearing clinic at Ball State University. Please call ahead to make sure the results are in (317/285-8162).

Mail to: Hoops--Speech Pathology
Ball State University
Muncie, Indiana 47306

Additional comments:

END OF QUESTIONNAIRE